

Illinois Office of Health Information Technology



Sensitivity of Patient Data: Safeguards for Certain PHI

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Illinois Health Information Exchange Authority Data Security and Privacy Committee

Introduction

Patients are generally more protective of their sensitive personal health information, usually because of the potential risks arising from the wrongful use of personal data associated with specific sensitive health issues.

Currently in Illinois, the following categories of patient health information (PHI) are afforded special patient consent procedures to permit disclosure of such data: HIV/AIDS; behavioral health; substance abuse and genetic testing.

Policy Question

To what extent should special types of "sensitive" PHI be treated differently for purposes of HIE exchange?

Federal Guidance

- Mental Health Data: The Federal HIPAA Privacy Rule currently requires patient authorization/consent for the disclosure of "psychotherapy notes."
- Substance Abuse Data: The Disclosure of data by a federallysupported substance abuse treatment facility is subject to regulations requiring patient authorization/consent.
- Genetic Test Data: The collection and use by insurance payers of genetic information is subject to restrictions under the Federal Genetic Information Nondiscrimination Act.

Illinois Status Quo: Mixed Opt-In/Opt-Out for Special PHI

- Special PHI: Opt-Out
 - HIV/AIDS consent for testing, except if for treatment or deidentified data.
 - Immunization registry consent for inclusion.
- Special PHI: Opt-In
 - Mental health/behavioral health/developmental disability, except therapist disclosures to staff.
 - Psychotherapy notes.
 - Substance Abuse.
 - Genetic test data, except if de-identified data or for program evaluation.
 - HIV/AIDS consent for testing insurance.
 - HIV/AIDS consent for disclosure of test results, except if de-identified data, program evaluation or for public health.